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Report of the Autism Spectrum Disorder Task Force



January 15, 2011

Interim Report

Task Force Members

Senator David Senjem

Senator Terri Bonoff

Representative Tara Mack

Representative Nora Slawik

Chair Dawn Steigauf - Autism Society of Minnesota

Vice Chair AJ Paron-Wildes – Parent

Dr. W. Brooks Donald – American Academy of Pediatrics

Dr. Jodi Milburn – Minnesota Academy of Family Physicians

Dr. Kimberly Klein – Minnesota Psychological Association

Dr. David Griffin – Minnesota Council of Health Plans

Renae Ouillette – Public School Student Support Services

Idil Abdul – Somali American Autism Foundation

Jean Bender – The Arc of Minnesota

Virginia Richardson – Parent Advocacy Coalition for Education Rights

Abdullahi Farah – Parent

Lydia Uphus – Staff

Legislative Charge

This report was prepared by the Minnesota Autism Spectrum Disorder Task Force in response to the following charge in Laws of Minnesota 2009, chapter 79, article 7, section 25.

- "(c) The task force shall develop recommendations and report on the following topics:
- (1) ways to improve services provided by all state and political subdivisions;
- (2) sources of public and private funding available for treatment and ways to improve efficiency in the use of these funds;
- (3) methods to improve coordination in the delivery of service between public and private agencies, health providers, and schools, and to address any geographic discrepancies in the delivery of services;
- (4) increasing the availability of and the training for medical providers and educators who identify and provide services to individuals with ASD; and
- (5) treatment options supported by peer-reviewed, established scientific research for individuals with ASD.
- (d) The task force shall coordinate with existing efforts at the Departments of Education, Health, Human Services, and Employment and Economic Development related to ASD.
- (e) By January 15 of each year, the task force shall provide a report regarding its findings and consideration of the topics listed under paragraph (c), and the action taken under paragraph (d), including draft legislation if necessary, to the chairs and ranking minority members of the legislative committees with jurisdiction over health and human services.
- (f) This section expires June 30, 2011."

Prevalence of Autism Spectrum Disorder

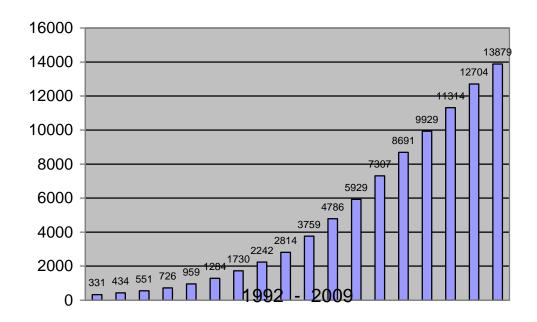
Autism is a complex neuro-developmental disorder that affects a person's ability to communicate and form relationships with others. Autism is currently thought of as a "spectrum disorder" meaning that the severity of symptoms differ in people with autism spectrum disorders (ASD). Those affected may have restricted, repetitive, and stereotyped patterns of behavior, interests, and activities. They may experience extreme sensory sensitivity and have difficulty with self regulation. Autism knows no racial, ethnic or social boundaries. Family income, lifestyle, and educational levels do not affect the chance of a child having autism. However, a Minnesota Department of Health and CDC report showed that Somali American children enrolled in Minneapolis Public Schools had an administrative prevalence of up to seven times higher.

According to the Centers for Disease Control and Prevention (CDC) report, about 1 percent, or 1-in-110, of 8-year-old children had an autism spectrum disorder in 2006. Among boys, the prevalence of autism was 1-in-70 in 2006. Between 2002 and 2006, the prevalence of autism increased by 57 percent, up from 1-in-150 children previously.

The chart below from the Minnesota Department of Education shows the increase in Minnesota students with ASD since 1992.

Autism Spectrum Disorders in Minnesota 2009 Child Count Trends for ASD – Birth to 21 years

Individuals Served under Autism Spectrum Disorders (ASD) Category MN Child Count Data



2010-2011 Task Force Work Plan and Presenters

The Autism Spectrum Disorder Task Force has met monthly since January 2010. The task force has followed the work plan developed during the fall of 2009. We have divided the work into 3 subparts chronologically. The task force has moved through early childhood and school age and is currently working on transition/adult services. We have developed a draft list of recommendations as we moved through each group. We will continue to work on the recommendations until June 30 2011, the sunset date of the task force. Our full report with all recommendations will be submitted to the Legislature by January 15, 2012.

Members continue to review information from current research, other states and presentations to the task force. The following people presented to the task force between January, 2010-January, 2011:

Kathryn Kmit – Minnesota Council of Health Plans

Mary Powell - Autism Society of Minnesota

Jennifer Larson – Holland Center

Dr. Kevin Wand – Midwest Wellness Center

Ann Kelly – Nutrition Ignition

Julia Sawyer – Parent Advocate

Ann Dudley – North St. Paul, Maplewood, Oakdale Public Schools

Lisa Hawthorne – Lakeville Public Schools

Robin Ostgaard – Lakeville Public Schools

Deb Thomas – Partners in Excellence

Stanley Hacker, Dr. Stephen Waisbren, Brandy Dougherty, Caroline Carritt, Joe Faulkner, and

Oscar Prill – Lionsgate Academy

Karen Balmer – Minnesota Board of Teaching

Sarah Thorson – Minnesota Department of Health

Ceci Shapland – Health Care Transition Issues

Amy Hewitt – University of Minnesota

Representative Kim Norton – Legislation Discussion

Representative Andy Welti – Legislation Discussion

Judy Strommen, Julie Sjordal – St. Davids Center

Pat Pulice - Fraser

John Sailer – Rochester Center for Autism Inc.

Ann Harrington – Celebrate the Spectrum

Various Community Parent Presentations

Recommendation

The Minnesota Autism Spectrum Disorder Task Force recommends that a task force with broad representation including the Minnesota Departments of Education, Human Services, Health, and Employment and Economic Development be convened to collaborate with other groups in the

development and implementation of an autism spectrum disorder statewide strategic plan encompassing awareness, early diagnosis, and a life-span of services for individuals with ASD.

It is the consensus of current task force members that the group should be broadened to include personnel from a wide range of departments. Their expertise would allow for better coordination and implementation of services for individuals with autism spectrum disorder. Minnesota needs a comprehensive state plan to provide a lifespan of services for individuals with ASD, while collaborating to use state and federal resources efficiently. Legislators on the current task force have shared their support for an organized task force going forward.

A driving factor for the continuation of a task force and development of a statewide strategic plan is the cost associated with the treatment of individuals with ASD. The Autism Society of America estimates that the lifetime cost of caring for a child with ASD is \$3.5-5 million. Autism costs America \$60 billion annually, and in 10 years that cost is estimated to reach \$200-400 billion. The Autism Society of America also reported that the cost of lifelong care can be reduced by 2/3 with early diagnosis and treatment. The development and implementation of a uniform state plan will aid in effective and efficient use of both state and federal dollars in the treatment of individuals with ASD.